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Stakeholder involvement in systematic reviews: a scoping review

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Background: There is increasing recognition that it is good practice to involve patients, health professionals, the public and others (stakeholders) in systematic reviews, but limited evidence about how best to do this.

Objectives: We aimed to document the evidence base relating to stakeholder involvement in systematic reviews, and to use this evidence to describe how stakeholders have been involved in conducting and producing systematic reviews.

Methods: We carried out a scoping review, following a published protocol. We searched multiple electronic databases (2010-16). Titles and abstracts were screened by one author, after determining > 95% agreement between authors. We completed pre-planned data extraction and judged the comprehensiveness of the description of methods of involvement. We completed additional data extraction for papers judged to have the most comprehensive descriptions.

Results: We included 291 papers in which stakeholders were involved in a systematic review. Patients and/or carers were involved in 30%. Thirty-two per cent were from the USA, 26% from the UK and 10% from Canada. We judged 10% (32) to provide a comprehensive description of methods of involving stakeholders. Of these, 69% (22/32) personally invited people and 22% (7/32) advertised opportunities to the general population. There were between 1 and 20 face-to-face meetings in 81% (26/32), with 83% of these holding ≤ 4 meetings. Meetings lasted 1 hour to ½ day. A Delphi method was used in 19% (6/32), most often involving three electronic rounds. Details of ethical approval were reported by 10/32. Expenses were reported to be paid in 8/32 systematic reviews.

Conclusions: We identified a relatively large number of papers (291) reporting stakeholder involvement in systematic reviews, but the quality of reporting was generally very poor. Information from a subset of papers judged to provide the best descriptions provides examples of different ways in which stakeholders have been involved in systematic reviews. These examples currently provide the best available information to inform and guide decisions around the planning of stakeholder involvement in future systematic reviews. This evidence has been used to develop online learning resources. Patient or healthcare consumer involvement: Three stakeholder representatives were co-authors on this review.